

**Table: Consolidated List of Discussion Groups' (DG) Recommendations for an Action Plan on Sickle Cell Disease in Adults**

Please note: Checks (✓) indicate DGs' recommendation of this component. Absence of a check means that a DG did not mention the component; it does not mean that the DG disagrees with the recommended component.

Recommendations and their components mentioned by Discussion Groups:	Health Care Group	Social & Econ. Group	Info & Educ. Group	Quality of Life Group	Fill Gaps Group
<b><u>Multidisciplinary, comprehensive health care model of clinical networks for adults</u></b>					
Pain management	✓	✓	✓	✓	✓
Day units	✓	✓			✓
Dissemination of best practices through technology, education, training	✓	✓	✓		✓
Psychological support/social work and related services	✓	✓		✓	✓
Need for establishing best practices in SC care for adults	✓	✓	✓		✓
<b><u>Quality of Life assessment and improvement</u></b>					
Need for development of SCD-specific QoL framework and measurements	✓	✓	✓	✓	
Component of clinical trials and research, and patient management	✓	✓	✓	✓	
Educational attainment, literacy including health literacy	✓	✓	✓	✓	
Work role and economic independence	✓	✓	✓	✓	
Family role, functioning and support	✓	✓	✓	✓	
Mental health status and access to services	✓	✓	✓	✓	✓
<b><u>Provider, patient, family and public health education &amp; information dissemination</u></b>					
Evaluation of existing materials and needs assessment for new materials			✓		
Repository of materials for different audiences			✓		
Media campaign and communication channels to reach audiences			✓		✓
Counter stigmatization, stereotypes	✓	✓	✓	✓	✓
Research to demonstrate effectiveness of educational interventions	✓	✓	✓		✓
Health care centers/networks and technology for disseminating information	✓	✓	✓		✓
Genetics education and counseling	✓		✓		✓
<b><u>Additional data and data systems</u></b>					
Social epidemiology of SCD, health care access, utilization and practice patterns	✓	✓			
Health objectives for adults with SCD: task force to specify objectives and data system to measure progress toward meeting objectives					✓